

#THENANDNOW

FND AWARENESS DAY 2024

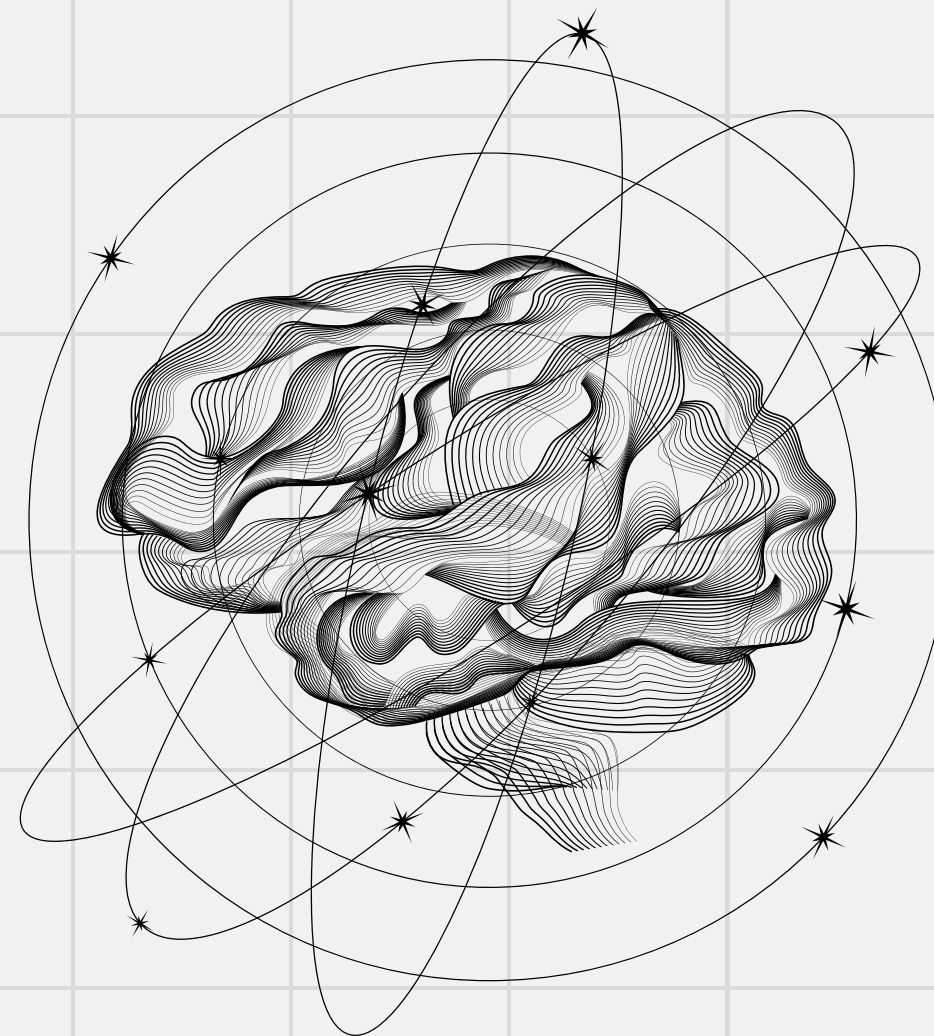
EFFIE B.



NEUROPSYCHOLOGY

RESEARCH IN FND

PRESENTATION



HOSTED BY:

FND ACTION
FND DIMENSIONS
FND FRIENDS



#VOICES4FND

ABOUT ME

Stephanie-Roxanne Blanco, BSc, MRes, Fhea

Publishes under: S.R.Blanco

Neuropsychology, mixed methods researcher, neuroimaging specialist



AFFILIATIONS

Lecturer in Psychology
Bishop Grosseteste University
PhD/ Guest Lecturer
Nottingham Trent University
Division of Neuropsychology



OUTREACH

Vice-Chair/ Medical Advisory
FND Dimensions
TEDx Speaker
Further outreach plans
10 years of patient support



RESEARCHER

Neuropsychology
FND Specialism since 2015
Lived experience
Currently submitting PhD
Looking toward my next steps



HISTORY OF FND RESEARCH

Research sits within a sociopolitical sphere and is influenced by social norms and values - regardless of the field



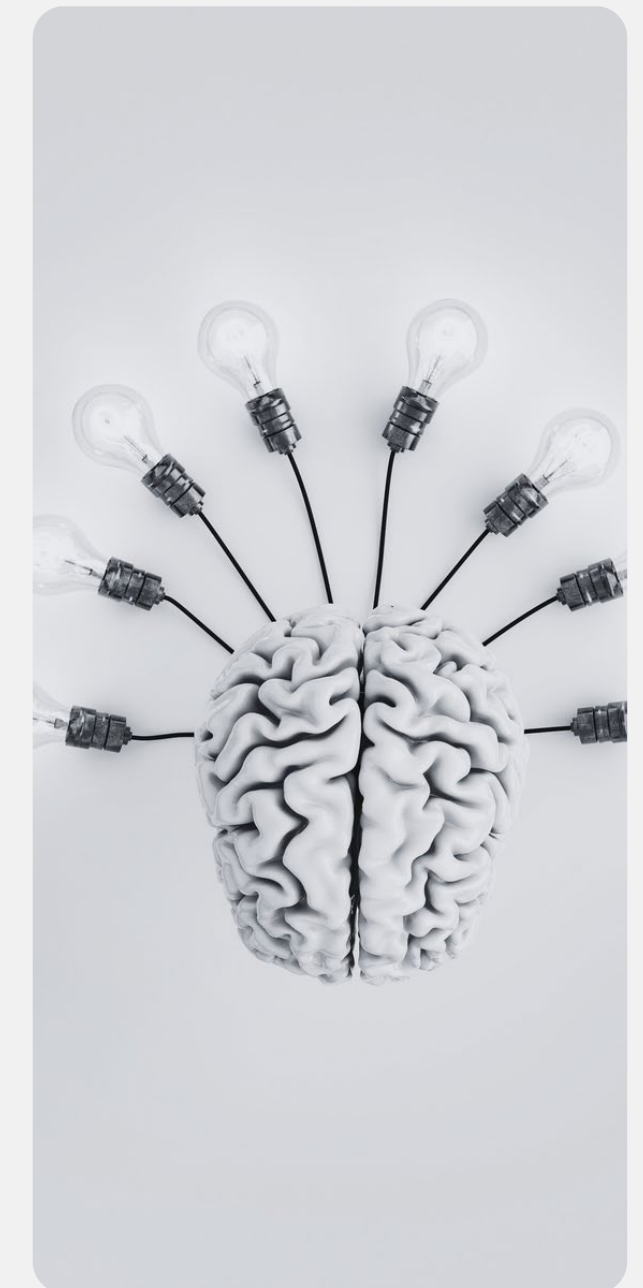
Anna O
Suffered from convergent squint, paralysis, paresis of her neck muscles, and contractures. Enters autohypnosis. Research linked to trauma and cures of talking therapies.



EEG: 1935. 3 Hz. Spike wave patterns epilepsy

1990s handful of publications in FND

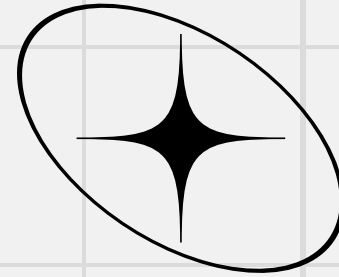
Early 2000s 2 lines of argument



1,210 peer-reviewed works since 2001

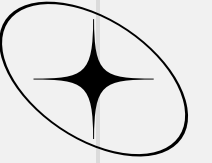
Research lines currently:

- What
- How
- Other



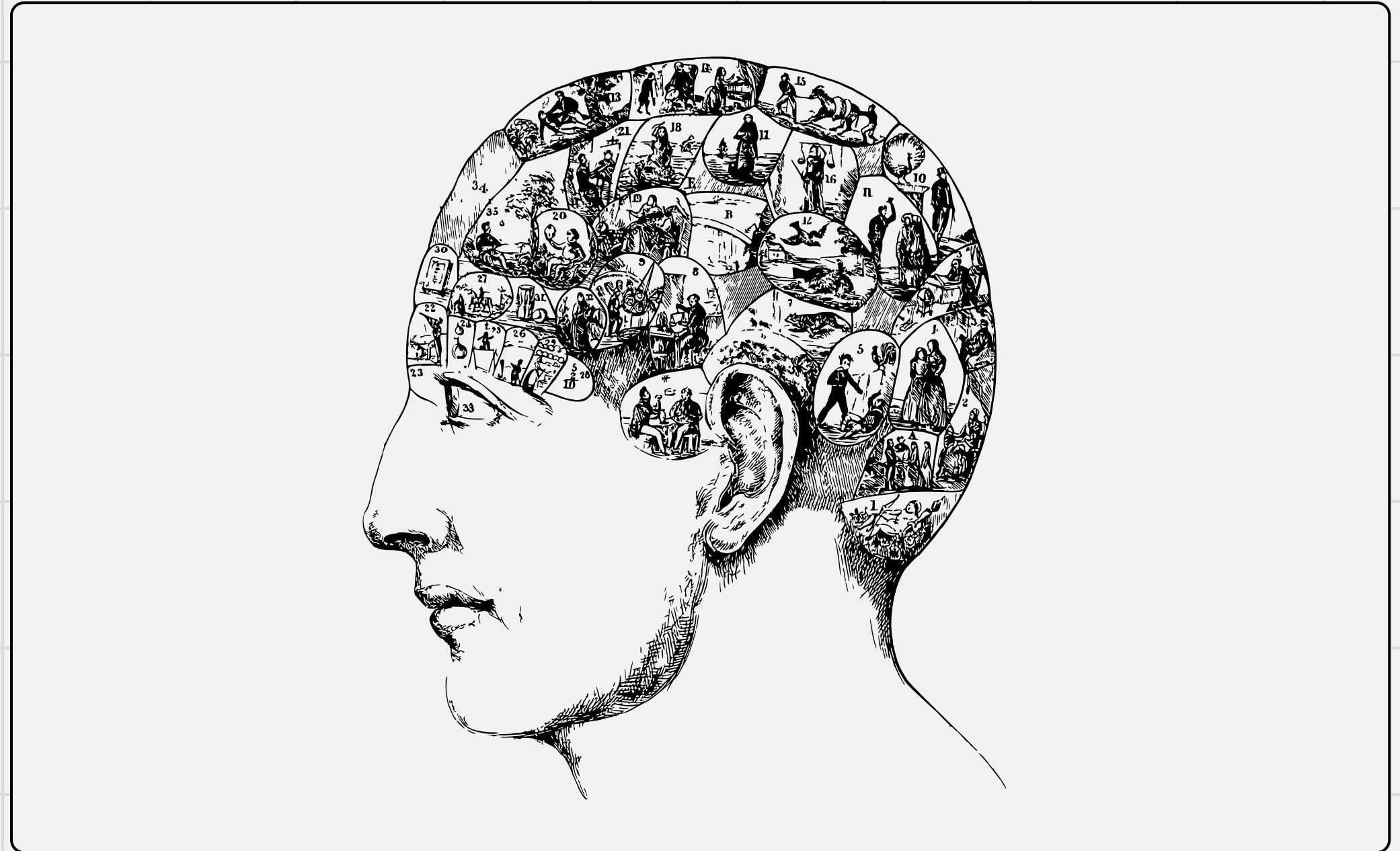
MYTH BUSTERS

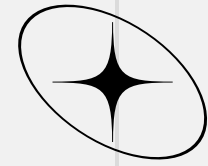




“FND DOESN'T SHOW UP ON A BRAIN SCAN”

We need to first understand how the brain functions



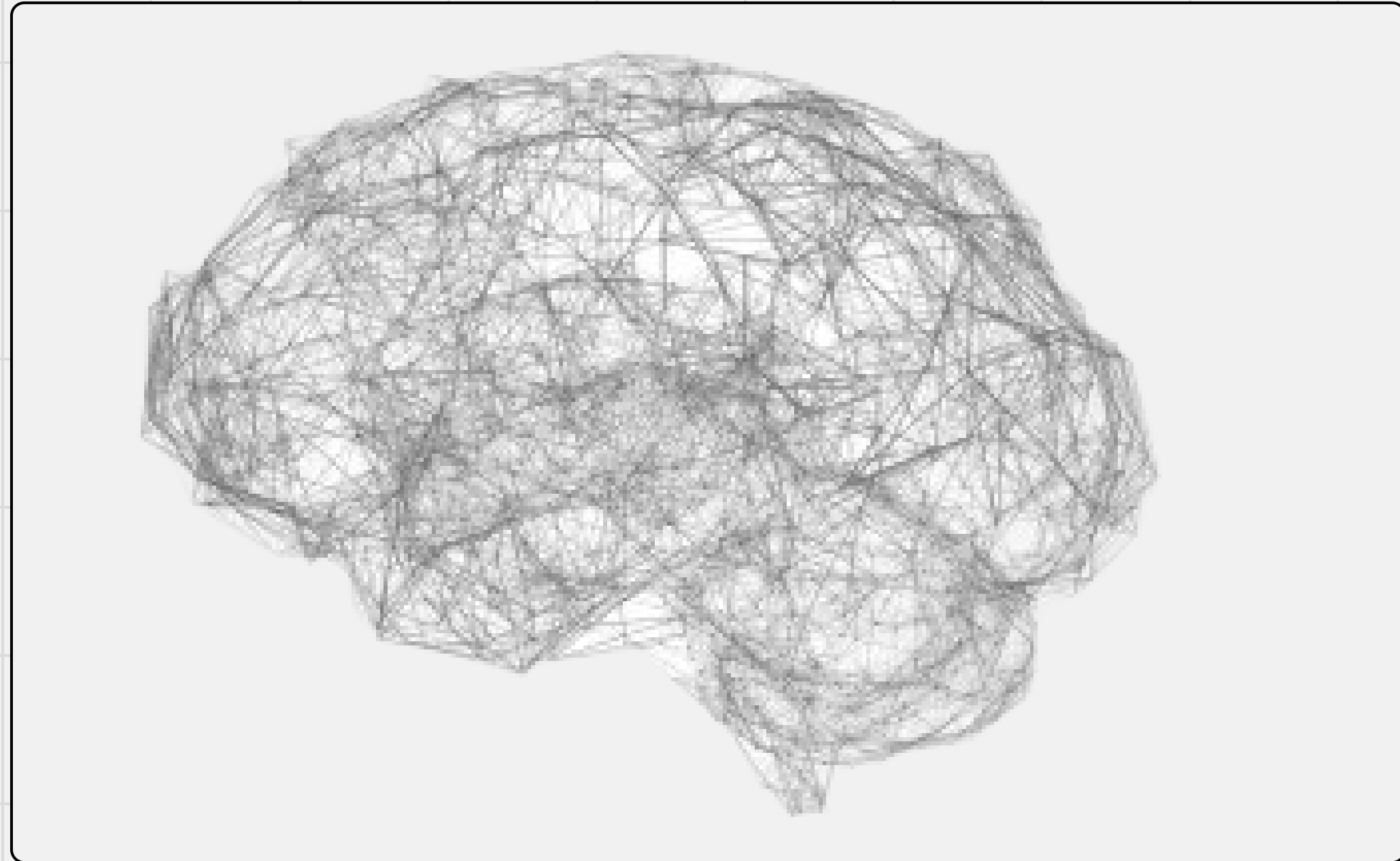


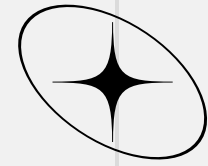
“FND DOESN'T SHOW UP ON A BRAIN SCAN”

FND suggested to be a neural network disorder

FND findings:

- Disruptions to rTPJ network in self-agency
- disruptions to motor conceptualisation, inhibitory control, attention, and others
- aberrant connectivity between cingular-insular amygdala and motor control networks





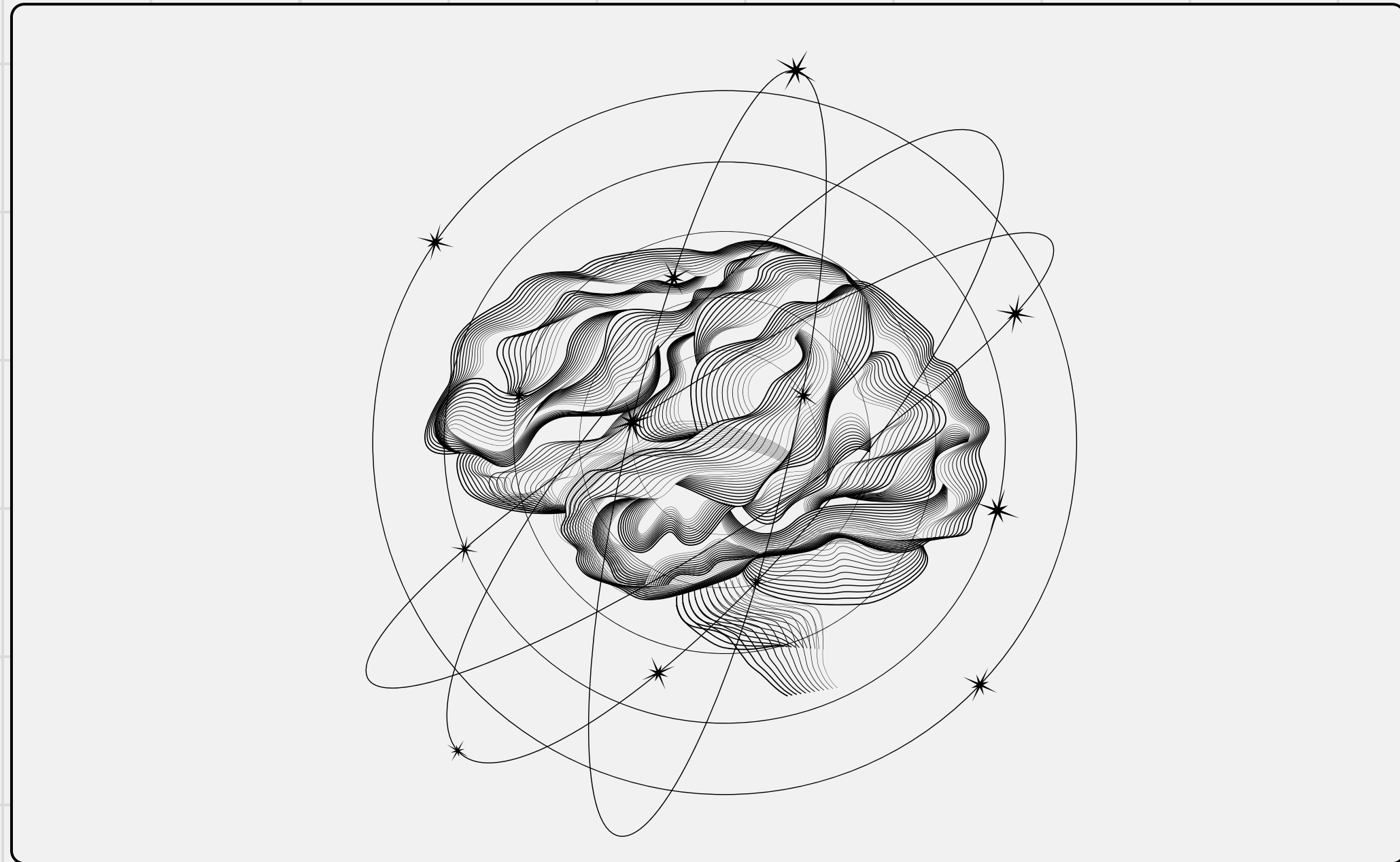
“FND DOESN'T SHOW UP ON A BRAIN SCAN”

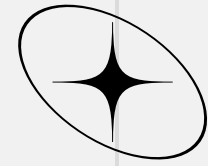
Even in a resting state, connections are disrupted.

Decreased resting-state connectivity between rTPJ and primary sensorimotor regions

F-seizures show differences in connectivity compared with motor subtypes

FND is more than a network disorder - brain, body and mind.



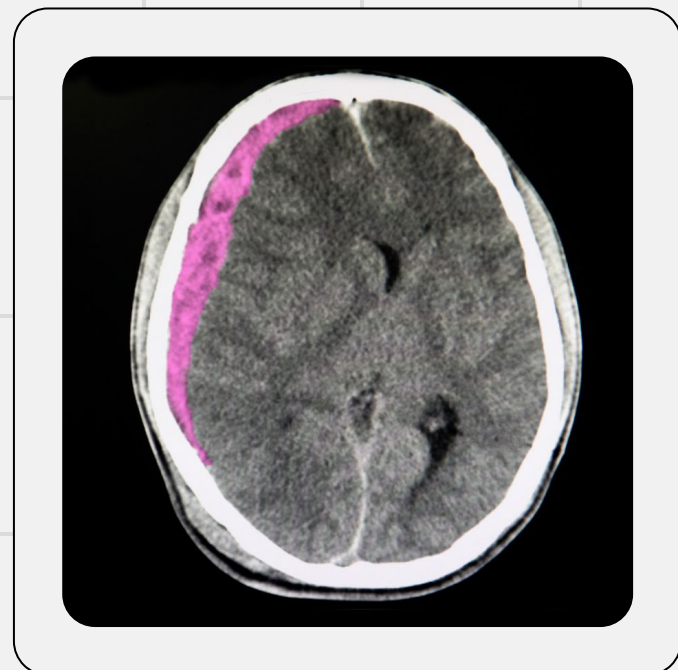


“IT’S A TRAUMA RESPONSE”

Trauma likely represents a subgroup of people.

Trauma lends to differences in function of the brain, as does infection, inflammation, head injury, etc

Dissociation is a strong predictor of FND but should be considered as a symptom, rather than a cause

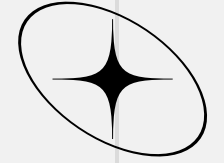


“THERE’S NO ROLE FOR PSYCHOLOGY”

Psychology goes beyond counselling. Research experts.

FND sits between many fields. All professionals should invest time to understanding this condition.

Grounding, pacing and other neuropsychological techniques can help to manage symptoms



“FND IS X REBRANDED”



FND is a distinct condition

There may be subtypes of FND (my current PhD explores this)

Assumed a general mechanism is operating in all FNDs

Why we use control groups



Comorbidity is high in FND

Fibromyalgia, CFS/ME, EDs, Chronic Pain, Migraines

As are other neurological disorders

Studies show high crossover between ASD and FND (studies in 2022)

Key next step is understanding prevalence, influence on treatment and prognosis



“NO-ONE’S TALKING ABOUT STIGMA”

Stigma impacts patients, access to healthcare.

Limits online presence/awareness raising

Researchers and clinicians do get targeted too!



A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder

Ciarán Foley^{a*}, Antonia Kirkby^b and Fiona J. R. Eccles^a

^aDivision of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, UK; ^bDepartment of Clinical Neuropsychology, Salford Royal Hospital, Salford, UK

ABSTRACT

Purpose: Functional neurological disorder (FND) causes many neurological symptoms and significant disability. It is often misunderstood by medical professionals and the public meaning stigma is regularly reported. The aim of this review was to synthesise the qualitative findings in the literature to develop a more in-depth understanding of how people with FND experience stigma to inform future interventions.

Method: This review used a meta-ethnography approach. Five databases were searched (PsycINFO, Web of Science, CINAHL, MEDLINE, and EMBASE) in February 2021 and updated in July 2022 for qualitative papers in FND. Included papers were critically assessed using the critical appraisal skills programme (CASP) checklist. Data were analysed and synthesised utilising meta-ethnography.

Results and conclusion: Sixteen papers were included in the final synthesis. Four major themes emerged: stigmatized by delegitimization; stigmatized by social exclusion and rejection; coping with stigma; and stigma and identity. The results identified negative, stigmatizing attitudes towards people experiencing FND symptoms in a variety of contexts including healthcare and other social institutions. The effects of stigma led to further exclusion for participants and appeared to trigger coping styles that led to additional difficulty. Stigma is a key part of the illness experience of FND and needs to be addressed.

ARTICLE HISTORY

Received 11 March 2022
Revised 28 November 2022
Accepted 2 December 2022

KEYWORDS

Functional neurological disorder; stigma; meta-ethnography; functional movement disorder; functional seizures

► IMPLICATIONS FOR REHABILITATION

- Functional neurological disorders can cause a significant degree of disability for those individuals who experience them.
- This experience appears to be compounded by stigma these people encounter as a result of their illness in their day-to-day lives as well as in their contact with institutions including education, workplaces, and healthcare.
- A potential strategy to reduce the impact of stigma is through raising awareness of the reality of this condition which may be achieved through education targeted towards healthcare providers.

Review

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Key words:

Functional neurological disorder; provider perceptions; conversion disorder; PNES; attitudes; training

Author for correspondence:

*Karen S. Rommelfanger
Email: krommel@emory.edu

Stigma and functional neurological disorder: a research agenda targeting the clinical encounter

Katherine E. MacDuffie^{1,2}, Lindsey Grubbs³, Tammyjo Best⁴, Suzette LaRoche^{5,6}, Bridget Mildon⁷ , Lorna Myers⁸, Elizabeth Stafford⁹ and Karen S. Rommelfanger^{10*}

¹Department of Speech & Hearing Sciences, University of Washington, Seattle, Washington, USA, ²The Treuman Katz Center for Pediatric Bioethics, Seattle Children's Hospital, Seattle, Washington, USA, ³Berman Institute of Bioethics, Johns Hopkins University, Baltimore, Maryland, USA, ⁴Brain Health Center, Emory University Hospital, Atlanta, Georgia, USA, ⁵Department of Neurology, Emory University, Asheville, South Carolina, USA, ⁶Epilepsy Center, The Mission Health, Asheville, South Carolina, USA, ⁷FND Hope International, Salmon, Idaho, USA, ⁸Northwest Regional Epilepsy Group, New York, New York, USA, ⁹National Alliance on Mental Illness, Arlington, Virginia, USA, and ¹⁰Center of Ethics Neuroethics Program, Departments of Neurology, Psychiatry, and Behavioral Sciences, Emory University, Atlanta, Georgia, USA

Abstract

Stigma against patients with functional neurological disorder (FND) presents obstacles to diagnosis, treatment, and research. The lack of biomarkers and the potential for symptoms to be misunderstood, invalidated, or dismissed can leave patients, families, and healthcare professionals at a loss. Stigma exacerbates suffering and unmet needs of patients and families, and can result in poor clinical management and prolonged, repetitive use of healthcare resources. Our current understanding of stigma in FND comes from surveys documenting frustration experienced by providers and distressing healthcare interactions experienced by patients. However, little is known about the origins of FND stigma, its prevalence across different healthcare contexts, its impact on patient health outcomes, and optimal methods for reduction. In this paper, we set forth a research agenda directed at better understanding the prevalence and context of stigma, clarifying its impact on patients and providers, and promoting best practices for stigma reduction.

THEN AND NOW

“IT’S A WOMEN’S PROBLEM”

Diagnosed in women more than men (3:1)

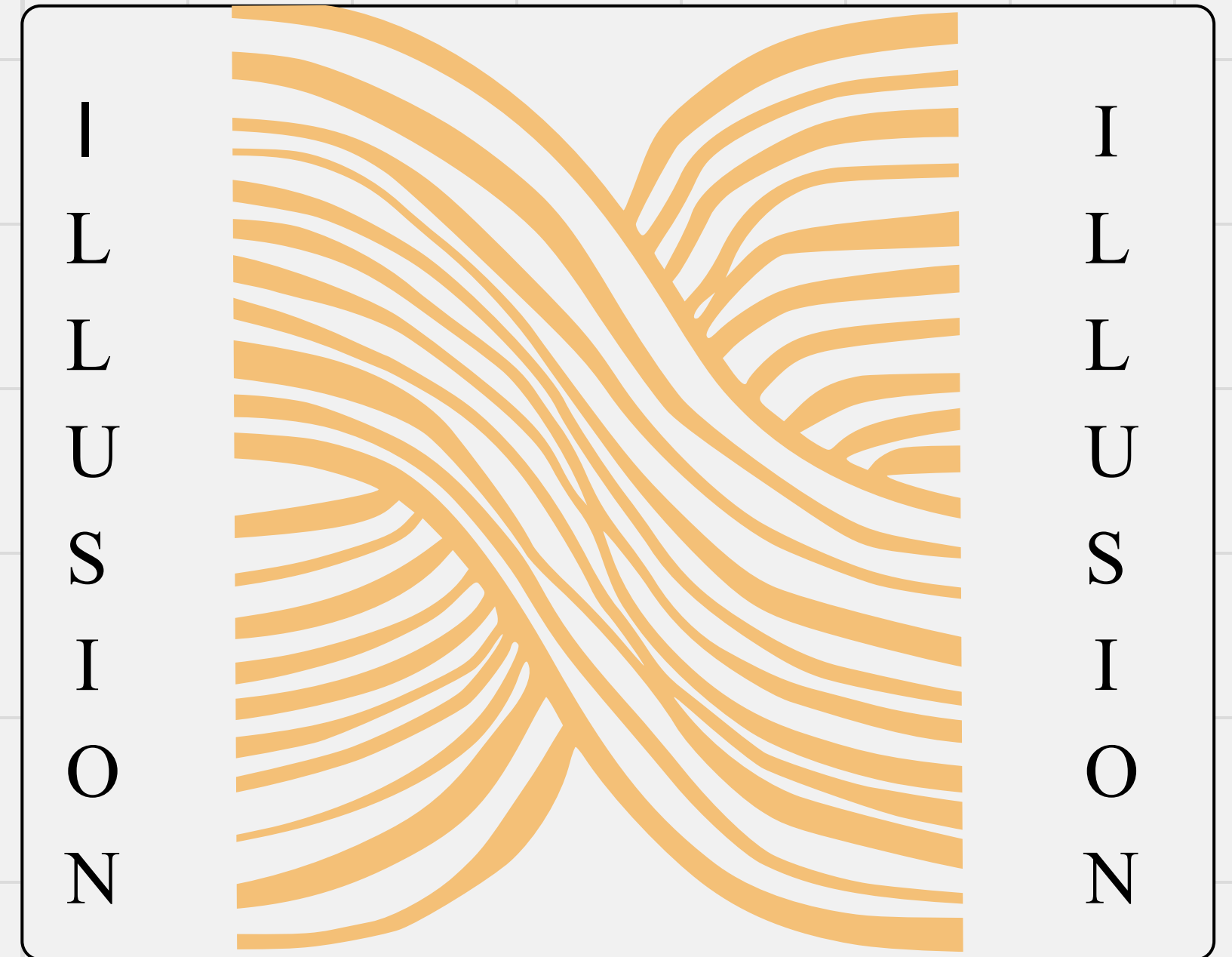
Historical biases leading to increased diagnosis in women?

Do not undermine men's experiences of FND

Lack of female-specific understanding, e.g. FND & childbirth, pregnancy, perimenopausal menstruation.

Socio-economic status

Other epidemiological studies urgently needed, LGBTQ+, BAME, culture in much the same way that it has been studied in other conditions

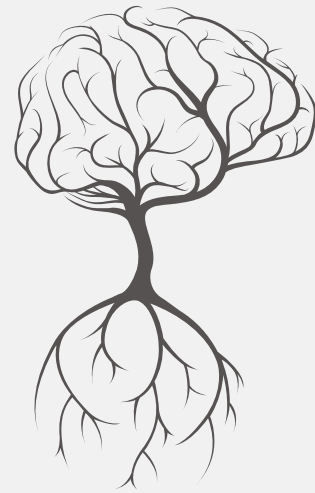


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OTHER RESEARCH AVENUES



CAUSES & MECHANISMS

Understanding risk factors,
epidemiology studies,
understanding lived experience,
biomarkers



CLINICAL

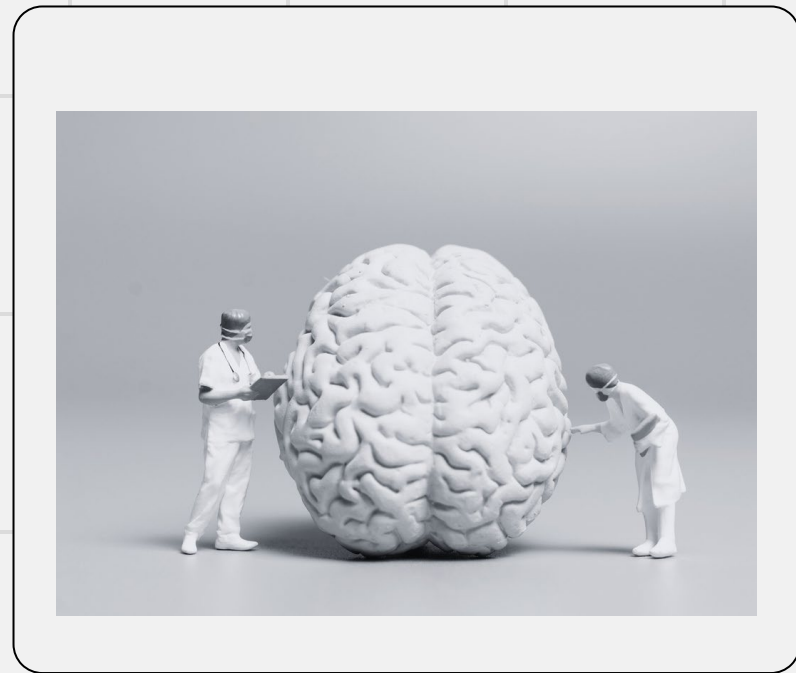
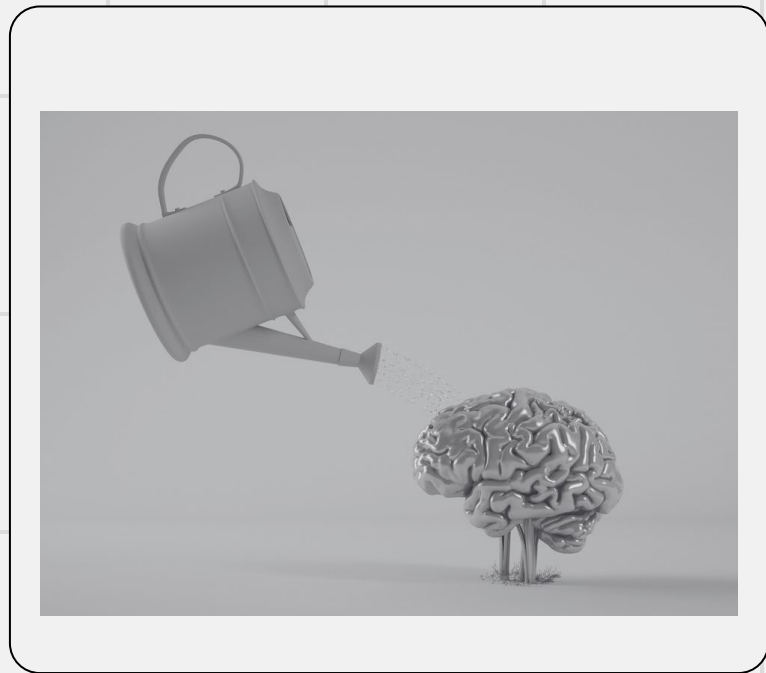
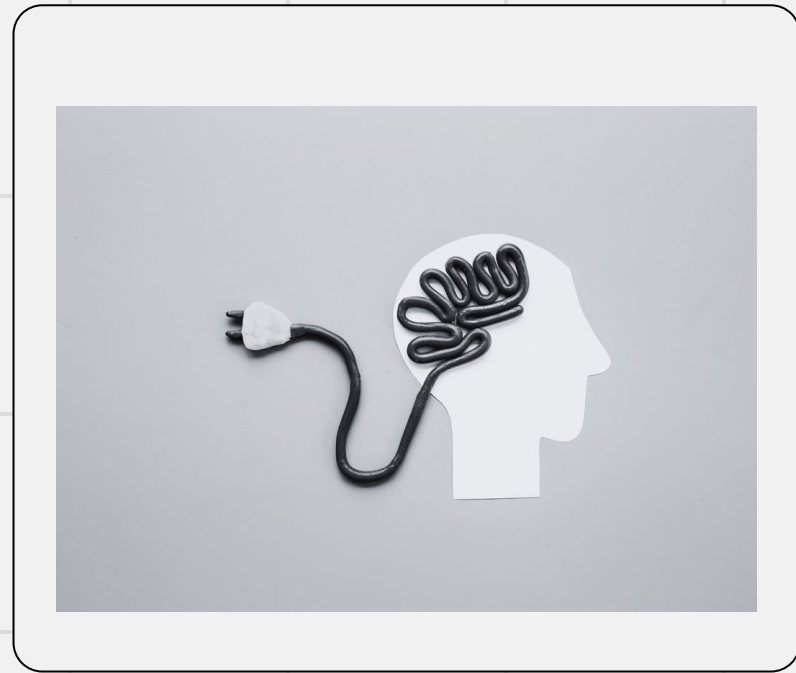
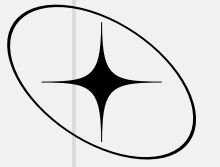
Improvements to diagnosis,
experience in healthcare and
categorisation to improve care
provision and outcomes



TREATMENTS

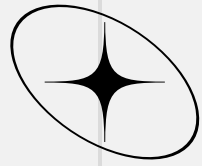
Whilst there's some research on
this, there isn't enough. This
needs to consider MDTs and
different symptoms





ANSWERS FROM RESEARCH





MY CURRENT WORK

Inflammation, dissociation and brain function in FND

Additional investigations into symptom profiles and types and influence on brain function, inflammation and dissociation



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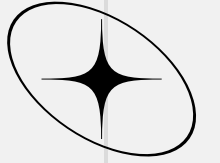
Other works:

- SNN in EEG
- Motor cognition pieces
- ERPs & other neuroimaging
- Other inflammatory markers and cytokines and omegas
- multi-modal analysis imagery & qualitative pieces

♡ 5K

🔗 5K

👤 5K



FUTURE OF RESEARCH

PATIENT PARTICIPATORY RESEARCH

NEUROIMAGING RESEARCH NEEDS TO
BETTER CATEGORISE SYMPTOMS

GREATER INCLUSION OF MORE
CONTROL GROUPS

LONGITUDINAL STUDIES

MORE MULTIMODAL RESEARCH

LARGER SAMPLES

MORE BIOMARKER STUDIES

GREATER COLLABORATION



THEN AND NOW

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EFFIE B.



NEUROPSYCHOLOGY

MY SOCIALS

Instagram @effiebee_neuropsychology

YouTube @EffieBNeuropsychology

LinkedIn Stephanie-Roxanne Blanco

Twitter/X @S_R_Blanco

THANK YOU Q&A

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